

Chapter Three

An Overview of the Alzheimer's/Dementia Experience Through both Science and Empathy

When you are Old

When you are old and grey and full of sleep,
And nodding by the fire, take down this book,
And slowly read, and dream of the soft look
Your eyes had once, and of their shadows deep;

How many loved your moments of glad grace,
And loved your beauty with love false or true,
But one man loved the pilgrim soul in you,
And loved the sorrows of your changing face
And bending down beside the glowing bars,
Murmur, a little sadly, how Love fled
And paced upon the mountains overhead
And hid his face amid a crowd of stars.

By William Butler Yeats

(This poem strikes so deeply because it touches on a
premonition in each of us.)

If we want to explore what a meaningful model of care should look like for our loved ones with Alzheimer's and other forms of dementia, we have to ask, what should be the goal of such a program? If we know that death is the inevitable outcome of the disease process, what should be the purpose or aspiration of such a model, for a life in such a transition? What is our ambition? If your dad died in my care, how do we say "we served him well? Is it cleanliness, stimulation, or safety? Is it exercise, comfort, or meaning? What should be the aspiration of our model of care? What would you want?

This is the threshold question, we should be all asking to define our path forward. The answer to this question should be the foundation upon which we can build a programmatic edifice. We can't define the strategy, until we have a result in mind.

The answer to this question for Peregrine, is that we believe that the overriding goal for an effective dementia program or model of care, is the challenge of maintaining the connection with one's self to oneself. **This is the first principal of the Peregrine Way.** As we begin to fade, how can we best maintain a grip on ourselves?

The great fear of one diagnosed with Alzheimer's is that they will lose themselves, forget themselves and in the process, their whole lives; living in nothingness. Being is suddenly nothingness. And the great fear of those families with a loved one diagnosed with Alzheimer's is that they will lose that person in time, as they fade away into becoming a stranger, a child, or a seeming idiot. Or as Shakespeare told us in *As You Like it*:

.... One man in his time plays many parts...
Last scene of all,
That ends this strange eventful history,
Is second childishness and mere oblivion....

This is the subject of the balance of this reflection, and should be the spiritual challenge of our generation. How do we keep vibrant souls engaged with themselves, their pasts, and their families, before they float away to the inevitable finale?

Collectively as a culture, I believe we need to establish values, priorities, and ambitions regarding the possibilities for the life experience of those afflicted by dementia that build on the psychological and emotional desires of our healthy selves, so as to further our individual journeys, our personal peregrinations. Ultimately, we should aspire to explore ways to maintain connections with ourselves. Because

as Dante says, we are all pilgrims, and just because we receive a diagnosis of Alzheimer's, it does not mean that the pilgrimage ends, but rather turns increasingly into the past.

As I have said, for many in the past and present, that model aspires to mere safety by embracing a custodial model of care, where total care is provided: we keep them safe, well fed, and clean. A patient is awakened, bathed, fed and parked in their wheel chair. Maybe bingo. But that is really all. Think of John 21:18. Very little thought about their souls, which are presumed gone, or happiness. This is what we commonly refer to as the "warehousing" of our seniors as we endure the prolonged morbidity of the disease process.

But for others with more ambition and imagination, it involves fighting the disease process through medications such as Aricept, and Namzaric, and now even jellyfish supplements, as we are all reminded daily by our TV's. And they complement these drugs with brain stimulation games such as Luminosity and Clevermind. But of course when those options fail to produce the desired results, and we tire, then we are back to custodial care. So we really only have one model of care: the institutional model.

To imagine an efficacious and compassionate model of care, I think we need to survey the dementia landscape, and make a brief review the following elements of the disease:

1. What can science tell us? What do we think we know and don't about the cause of this disorder, and what is the role played by genetics? I think you will be disappointed and confused by our lack of clarity.
2. Consider if Alzheimer's is even a disease or simply old age. This is a critical question, because if it is just old age and there is no disease culprit lurking in the shadows of our microscopes, then it throws our obsession with a cure into something comparable to alchemy. This was something very much in vogue with "modern" science until relatively recently, and akin to science banging its head into a wall.
- 3 Review the cognitive stages of the dementia descent. While the disease process is unique to each victim, the overarching trajectories are predictable and clear. Like tracks in the snow, the disease process can easily be followed offering common sense insights into models of care.
- 4 Then I will try to imagine or recreate the actual experience of the dementia journey. If we can gain glimpses into the surges and swales of the seagoing voyage of someone with memory loss, maybe we can garner some insights as to how we would want someone we loved to be cared for, and how we would want to be treated.

Perhaps then, after surveying what we do know or can reasonably imagine, we can aspire to move from our current

model of care and start to address the deficits created by Alzheimer's and other forms of dementia, and try to erect buttresses for those deficiencies.

To start, we know remarkably little about the disease known as Alzheimer's, which accounts for up to 70% of the types of dementia which total over the eighty we catalogue. Obviously, there are other forms of dementia that merit an explanation as to their etiology such as vascular dementia, Lewy Bodies, and late stage Parkinson's disease, but these will not be evaluated in this book as our primary concern is Alzheimer's, the dominant threat. But a good quick overview of these other form of dementia is available in "Alzheimer's Disease Decoded" by Ronald Sahyouni, et al.

For an excellent explanation of the conventional description of the Alzheimer's disease process, I suggest one review Dr. Peter Whitehouse's "The Myth of Alzheimer's." In that book, he points out that Alzheimer's is an irreversible degeneration and death of brain cells that lead to atrophy and brain shrinkage. The main agent in the brain shrinkage of neurons are thought to be what is commonly called plaques and tangles (amyloid beta) of protein deposits. These accumulate in the hippocampus, caudate nucleus, and prefrontal cortex. And this is what Dr. Aloisius Alzheimer discovered in abundance when he performed an autopsy of his first patient afflicted be the disease, Auguste Deter in 1906. One is tempted to imagine the interactions of the tangles and plaques and our brain cells in anthropomorphic terms such as

“strangling”, “pruning”, or “high jacking”, but regardless of the preferred verb, the neurons cease to function and die. And as those parts of the brain are impaired, their respective functions are debilitated commensurately. It is estimated by some, that an Alzheimer’s victim can often lose 50% of their brain mass.

To appreciate this disease process and how it relates to the loss of short term memory, it should be kept in mind that the initial primary target of these protein deposits is thought to be the hippocampus, which is the part of the brain that controls our short term memory. In 1943, this was discovered when surgeons removed the hippocampus of a patient in an effort to cure his epilepsy. While the operation was largely successful in its purpose, the unintended consequence was that the patient was unable to recognize new people or retain new facts. For the rest of his life, the patient lived in the present though he could still retain older memories as they were stored in parts of the brain outside of the hippocampus.

It should be noted that there are two basic types of Alzheimer’s: early on-set dementia which effects those between the ages of forty to sixty which accounts for about 5% of those affected by the disease, and “naturally occurring dementia” which usually starts at about the age of seventy five. Of these two broad categories of this condition, early on-set dementia, is clearly inherited and genetically tracked. An afflicted parent has a 50% chance of passing the disease on to a

child. Naturally occurring dementia, according to Rudolf Tanzi, may be caused by up to one hundred genes that could be involved in the creation of this condition, thus creating a possibility, but not the relative certainty of the disease. Science tells us that there is an “Alzheimer’s gene” referred to in shorthand as the APOE4 gene. Americans that carry two copies of the gene are 10 times as likely to develop the late-onset form of the disease according Pagan Kennedy.

What we thought we knew about Alzheimer’s’, is questionable. For example, as Whitehouse tells us, maybe plaques and tangles are a defensive brain reaction to inhibit enzymes that causes the death of the neurons, Whitehouse speculates .

The plaques and tangles theory has two problems. First of all, we don’t understand what causes their production, or in the words of Joseph Jebelli in his recently published “In Pursuit of Memory”, “In truth, however, we’re still not entirely sure what they are, why they form, or how they cause the disease”. It is of course difficult to produce a cure for a disease, when we don’t understand its cause.

The second problem and what really threw the tangle and plaque scenario into chaos was the 2001 study of the members of the Sister of Notre Dame that revealed that many of their deceased members had significant presence of these tangles and deposits on their brains, but exhibited no evidence

of cognitive deficits in their lifetimes. And later we realized that these were common presences in many older people regardless of one's cognitive abilities.

Changiz Geula, a professor of neuroscience at Northwest University has brought this issue into startling clarity after performing autopsies on people who died after 90 years old and discovered that some people who died with sharp minds have brains that are “clogged with gunk associated with Alzheimer's' pathologies.” This means that it's possible to have an “Alzheimer's brain” but no dementia, (See P. Kennedy). Like Whitehouse, Dr. Geula believes that there is some biological mechanism in the brain that counteracts the debilitating effects of the disease. This remains a great mystery.

This realization has opened the debate as to whether Alzheimer's, other than early onset diagnose, is even a disease or simply the natural and uneven aging process of the brain.

The leading advocate for the position that other than early onset dementia, most dementias for someone in their 70's or 80's is not a disease but the natural aging process, is again Dr. Peter Whitehouse. Once a leading clinical researcher on finding a cure for Alzheimer's and working for the large pharmaceutical companies, now a staunch opponent against labeling Alzheimer's a disease and the preoccupation with finding a cure, at the

expense of focusing on care. He states in his book “The Myth of Alzheimer’s”

“No longer can we safely assume that the march of progress in the “War against AD (Alzheimer’s Disease) is moving at the hoped for speed or direction; no longer can we maintain the mythical illusion that AD is a battle against a specific disease that we will eventually “win”; no longer can we keep looking at aging persons, however embattled, as somehow “diseased.” Defining brain aging as a disease and then trying to cure it is at its root unscientific and misguided. In short, Alzheimer’s is a hundred-year old myth that is over the hill. The entire scientific, technological, and political framework for aging needs to be reassessed to better serve patients and families in order to help people maximize their quality of life as they move along the path of cognitive aging.”

To bolster his view, Whitehouse makes a close examination of Dr. Alzheimer’s work and reflection. In reviewing Alzheimer’s own papers he reveals even his uncertainty. Dr. Alzheimer encountered a relatively young woman of 51 known as Auguste D, that was losing her memory and mind. Upon her death, he performed an autopsy and discovered the now famous protein amyloid deposits in her brain. This was soon defined as a new brain disease by his superior, but not Dr. Alzheimer.

But when Dr. Alzheimer wrote in 1911 about his discovery he said “the question arises whether these cases of

disease, which I have considered as peculiar, still show characteristic features in clinical and historical aspects that distinguish them from senile dementia or whether they must be assigned instead to senile dementia itself”.

Not even Dr. Alzheimer’s knew with certainty if what he discovered was a “disease” after an autopsy of his profoundly demented patient. But remember, Dr. Alzheimer’s was dealing with an early on- set dementia patient. She was only 56 when she died.

What we thought we knew was about protein tangles and plagues in certain parts of the brain that damage certain functions that control short term memory, seemed to make sense. There seemed to be a logical cause and effect. And in fact that view largely still reigns, thus the ongoing preoccupation for a cure.

But in a larger sense, whether Alzheimer’s is a disease or not is beside the point. If one loses brain functions as a result of a disease, or old age, is largely irrelevant to the question of care. If it is a disease for which there is currently no cure, or old age, which also has no cure, we still need to consider care models. Where this question is relevant however is in regards to the preoccupation of a cure. If Alzheimer’s is not a disease, except for early onset dementia, and the natural aging process, then the preoccupation with a medical breakthrough, is at best misplaced. (Do we need to be reminded that even Isaac

Newton, the inventor of Newtonian physics, explicator of gravity, and pioneer of calculus, practiced alchemy?)

Stages of the Disease Process

The narratives of the effects of the disease process of Alzheimer's are many but I prefer the sequencing outlined by Naomi Feil, the great pioneer in the field of dementia care as it is consistent with my experience. She offers four stages of decline in her 1993 book "The Validation Break Through":

One, Malorientation. This is what we commonly refer to the early stages of dementia. One knows something is changing in their cognitive abilities and are typically in denial and angry. The earliest pronounced symptom for the afflicted is the diminishment of short term memory. We get lost coming home, forget our last meal, and having trouble with the names of new friends. (When my 87 year old mother moved into an "independent" living community she always dreaded going to dinner because few could remember the names of the other residents, much less their friends.) These people can still care for themselves though they sense the walls of their independence are closing in. They are depressed, terrified, and frustrated. When I discussed the soul never aging in Chapter Two, it is important to distinguish the brain aging from the soul

aging. They still identify themselves, but realize their brain is failing, just as their sight and hearing is failing.

Two: Time Confusion. This is what we commonly refer to as moderately advanced dementia, where we lose track of time and even place. This is when dementia becomes a crisis as the individual can no longer care for themselves or safely be left alone. They forget family, friends and even sometimes their own names. Short term memory is decimated and judgement is being felled. They have lost the ability to sometimes reference their location, or even their hour, day, or month. They have become lost in time, which keeps moving by at a bewildering and uneven rate.

Three, Repetitive Motion. This occurs when one is left alone, withdraws and expresses themselves through a repeated gesture or expression. I had one resident that repeated the word apple constantly. Others have played an invisible piano, or touched the face of their ghostly baby infant.

Four, Vegetative State. This is what some would darkly call the Living Dead. There are little verbal skills, eye contact, or recognition. They live entirely in the past.

There are many dimensions of cognitive ability in decline through the disease process, but the overriding and defining affect is the erosion on our sense of current time and short term memory. We are left in a dislocated present or past.

Imagining the Disease Experience

The important issue to appreciate is that as the short term memory fails, people with dementia live increasingly in their past, and at the whim of time. Time travel becomes possible, and it happens constantly with this population. I am reminded of Greg O'Brian's memoir of his own experience with Alzheimer's when he writes in "On Pluto; Inside the Mind of Alzheimer's": "Yesterday, I was flush with hope; today I am adrift in thoughts and images, I can't seem to control them. They rule me. Often, I just go with the flow." This observation echoes E. B. White, who wrote *Charlotte's Web*, and also had dementia, when he said, "So many dreams-its hard pick out the right one".

To distinguish between the thought process and mental experience of someone in the early stage of Alzheimer's (Malorientation) and moderate stage (Time confusion), perhaps the earlier stage could be imagined as walking on cracking ice. Short term memory is failing but still offering some support, though unsteady. Thoughts become jagged and uncertain. Conversations, dangerous. You may feel like you are clinging to the walls of a cave as you inch along in time and space, grateful for the stability but you remain aware of the walls have limited value if you wanted to roam the rest of the space. Perhaps feeling mildly, and unhappily drunk.

In moderate Alzheimer's, or the Time Confusion stage, the walls are largely gone. The present is merged with the past and those two dimensions of time swirl between themselves. We are less of a rock in a river, than one caught in the shifting currents and tides of the sea. I am reminded of the following poem:

Alzheimer's by Bob Hicok

Chairs move by themselves, and books,
Grandchildren visit, stand
New and nameless, their faces' puzzles
Missing pieces. She's like a fish

In deep ocean, its body made of light,
She floats through rooms, through
My eyes, an old woman bereft
Of chronicle, the parable of her life....

Let me now try to imagine the mental and physical experiences of some one experiencing Alzheimer's has been shared to me by my residents. If I am in early stage dementia and walking on a damp lightly raining day to the drug store, I spend my mental energy reminding myself of my direction, wet shoes, and purpose. "Yes, two more no, blocks and then a right, steady, to pick up something for Mary, aspirin? No? Aspirin. I think it was. Yes. Quickly, don't give myself away now. Strange old fat lady staring soaked. Purpose, quickly. Short sentences,

eye contact. Hurry, need to get home..., no, still need to get to the store. Forgot! Oh, that's kind of funny, losing my friggin mind, still need to get the grocery store. Ok, now which way to Old Duffy's smelly saloon, miss that old three legged dog, must be dead by now years ago, came to me last night in a dream, funny dreams you have when you get old, only knew two three legged dogs in my life, Duffy and King, always my friends when I had none, a lonely little lad. What was it about me and the three legged. Licking, trying to jump up, and tripping so sweetly, smiling almost. No, it is the fucking drug store, aspirin. Now which way? Straight, two blocks, hope no one watching me wander..."

But if I am in a moderate phase on the same damp walk, I am thinking about a bright spring sunshine, and after Mass treats such ice cream and chocolates. "Mother was wonderful, but so sad, tired all the time. Priests never nice to her either, always whispering to red faced Dad. Always judging Mom, laughing not nicely, frowning. Where is Mom now? Beautiful in pink flowers. Dressed up for church. Pale. Home maybe? Waiting with treats? Hungry for her treats. Lost now! Mother? Mother? Which way? Agh, pants wet, must be leaking, shit. She'll be angry with me. Must get home quickly, to hide smelly pants....Cars look so strange and small....did good at church today, didn't drop Jesus, the wafer, oh, till the priest come judging

me. Frowning, that was humiliating, couldn't move for an eternity staring at the body of Christ on the burgundy and gold carpet, helpless, but not today, wife would have let me have it for a week, silent treatment, if I dropped communion, not Mother, though. She felt so bad she didn't say a word, silently she give me extra treats combing my hair in her soft hands.....Mother..."

Trying to imagine the thought process of these two stages of Alzheimer's is of course speculative at best but possible because discussions are still possible and experiences can be expressed and impressions shared. But imagining the stream of consciousness of someone in Repetitive Motion stage of Alzheimer's is more challenging. I will discuss this further in Chapter Five when I revisit my friend Maria, and her apples.

I would like to add to this overview of the life experiences of someone with dementia, three additional common sense observations that are often misunderstood:

First, when adult children complain that their mother doesn't recognize them I tell them: "your mom doesn't know your face or name because you have lost most your hair, you are now largely gray, and gained 40 pounds; "maybe you really do look like Uncle Bob?" They are looking for their children in their past and you may not be there. Their spouses and

children are not forgotten, they are rather, not recognized. It seems fairly obvious to me that when one retains a youthful appearance, they are less likely to be forgotten.

Besides the loss of memory, is a second consideration which should be kept in mind when dealing with someone with dementia, is that other senses are failing as well as their minds and memories: hearing, sight, taste, balance etc. This collective system failure contributes to a withdrawal from their immediate world and pushing them further into isolation. And when they often slam with increased finality into their long term memories, they are trapped there through the double isolation of loss of short term memory, and their failing six senses and frailty; they are trapped and left to contemplate time gone by, and with very little to distract themselves from their outside worlds.

A third element defining the experience of someone with Alzheimer's is the fact that many long term memories were traumatic and had been successfully suppressed for decades. But as the screen and distraction of short term memory recedes, and the body fails, these old memories, can come on with a vengeance.

When a dementia victim tells me that there is a man in her room, I assume she is not hallucinating but expressing a fact of her unresolved experience in her long term memory. When a resident tells me her father just called about picking her up for dinner, I don't remind her that her father died years ago in a

car accident coming to pick her up in a snow storm, I assume they just spoke and she has never resolved her misplaced guilt over his untimely death. Naomi Feil teaches us, taking a cue from Sigmund Freud, that all behaviors, no matter how bizarre to healthy observers, has a cause in actual experience in one's past. Later, in Chapter Six I will discuss Naomi's suggestions on how these challenges can be partially ameliorated.

Once we appreciate the profound and controlling nature of long term memory, it makes the preoccupation, no obsession by our medical and pharmaceutical communities, and the "brain game" communities, with saving and stimulating short term memory, seem to me tragic. They miss a glaringly obvious point and are looking thru the wrong end of the telescope.

To understand how to communicate, empathize, and comfort a loved one with dementia or Alzheimer's, one must start by going backwards. By going into their past, the behaviors and needs all will begin to make more sense and the effort to understand and empathize with their obvious mishandling of their attempts to interact through their short term memories, will become better understood.

Time to be sure still moves forward for them but rather than imagine them living watching a single reel of their past unfolding life, it is probably more like a series of mini films that start rolling when an event, person, smell or sound stimulates

memories, good or bad. Time still flows forward, but in smaller increments over past sequences in our memories.

So if we aspire to a model of care for our loved ones which is comforting, gently stimulating, and meaningful, it will not be achieved by manipulating their short term memory, but thru their long term memories. And in my experience, and what is obvious to any experienced care giver, we need to reach out to one's joyful long term memories . **This is the second principle of the Peregrine Way** and informs all of our ideas underpinning our model of care, from how we design a memory care community, our emphasis on spirituality, and of course, how we can help maintain a connection between our residents and themselves.

Many of our medical experts would find this a counterintuitive approach as they toil perfecting their diagnosis techniques, and futile prescriptions. But from Peregrine's perspective, science's pre-occupations with stimulating and preserving short term memory, while offering no cure is a recipe for frustration, unhappiness, and abandonment. It is an often quoted directive among memory care providers that we need to "go to where our residents live". Well, where they live is in their pasts.

In closing this chapter, I want to point out one of the great ironies of Alzheimer's disease in the context of one of the great

intellectual rivalries of the early 20th century. In Austria and Germany at the turn of the last century, the psychological world was turned on its head by Sigmund Freud's "Interpretation of Dreams" where he rather convincingly argued the many psychological problems could be traced to our pasts and the uncontrolled impulses driven by our unconscious and subconscious experiences. Often these were sexual in nature and born by our infantile and formative years.

Alzheimer, on the other hand, was in search for biological and organically based causes for psychological abnormalities, like tangles and plaques. In some ways, Freud was seen as playing an unscientific guessing game, more an artist at best, but no scientist. While Alzheimer was searching for cause and predictable effect: predictable and verifiable results. While Freud seemed to feel he discovered a new continent and appears to have had little interest in the work of his Teutonic contemporary.

But the truth, seems to be somewhere in the gulf that separated them. Alzheimer's and other forms of dementia seem to have organic causes, or organic failures, but models for appropriate care to give comfort and meaning seems to be rooted in the embrace and respect in the long term memories and goblins of the past; whether forgotten or joyfully surging, suppressed, or searing. Freud has much for us to consider, and it is a shame he never seems to have considered the problem of dementia. Most intellectual schools are at least partly wrong, and partially a boon. But as long as our culture keeps looking

for a cure and not care, our suffering and the suffering of our isolated loved ones and their families, they will continue in the darkness of their memories.